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ABSTRACT

The report describes policies and services for individuals with developmental disabilities in Minnesota. It emphasizes changes in the way of thinking about individuals with developmental disabilities as knowledge increases concerning what they are capable of doing and what is important in their lives and how they can be supported in communities. The report notes that incidence of developmental disabilities in the Minnesota population, outlines the needs of individuals with developmental disabilities, and notes that they are more like the rest of the population than they are different from it. The new way of thinking stresses supporting individuals, families, and communities. A new perspective on policy is offered, along with an overview of the history of services to people with developmental disabilities. Educational services from preschool to adult vocational programs are described. A section on new living options discusses returning people to communities, developing alternatives to regional centers, and establishing more individualized settings. Alternative approaches to traditional job placement involve rehabilitation services, developmental achievement centers, and integrated employment opportunities. A final section examines mechanisms needed to support the new vision (federal funding reforms, alternatives to institutional care, and promotion of individualized options) and notes what Minnesotans can do to support the vision, as consumers and parents, policymakers, professionals, citizens, and communities. Photographs, quotations, tables, charts, and graphs illustrate the text. (36 references.) (JDD)

A NEW WAY OF

Thinking

Governor's Planning Council on
Developmental Disabilities

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Chris, 16 years old
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A NEW WAY OF

Over the past several years, we have learned about people with developmental disabilities, what they are capable of doing, what is important in their lives, and how they can be supported in communities. From what we have learned we are changing our way of thinking and our way of acting. A parent and leading professional in the field, Toni Lippert has observed the following changes in Minnesota:

- A shift from expanding system *capacity* to increasing service *quality*.
- A move from fixed and predetermined expectations of persons with severe disabilities to higher and more demanding expectations by the individuals themselves, their families, and service providers.
- A move from short-term, developmental planning to life-long functional planning.
- A move from providing a service continuum with emphasis on special facilities and programs to seeking a service array that adapts generic resources by providing the assistance and support as needed.
- A move from a fragmented grouping of separate and independent services (residential, day training, education) to recognition of the need for a holistic, interdependent and integrated service system.
- A move from a system of offering models of service delivery to one where it is possible to create individualized support.
- A move from service payment based on facility budgets toward reimbursement based on vendor performance and individual needs (Toni Lippert, personal communication, 1986).

Dan, 16 years old
receiving assistance

While we did the best we could based on what we knew, it has now become clear that funding will have to be reorganized to support meaningful change.

Regulations governing use of federal funds (Medicaid) often determine both the shape of public policy and the type of services provided. We have been very creative and effective in using funding and policy opportunities to provide services. Much has changed, but not enough. We need to use what we have learned to shape the system so we can move beyond a focus on maximizing federal funding to one of building opportunities for people with developmental disabilities.

Who Are the People with Developmental Disabilities?

One way of thinking about people with developmental disabilities is linked to definitions and numbers. Historically, services were provided to those Minnesotans who were diagnosed as "mentally retarded." In 1985, however, the Legislature recognized people with "other related conditions" and made them eligible for services (M.S. 252-27, Subd.1).

The official definition of "developmental disabilities" is contained in the Developmental Disabilities Act of 1984. The federal definition is based on the nature of the impairment (mental and/or physical), the age of onset and the long term nature of the disability, the substantial effect on the individual's ability to function in several major areas of life activity, and the degree to which the person needs ongoing services. People with developmental disabilities are considered to be those people with the most severe disabilities. A commonly asked question is how many people with developmental disabilities are there in Minnesota? While there is no definitive answer, the

A developmental disability is a severe, chronic disability which:

- Is attributable to a mental or physical impairment or a combination of mental and physical impairments.
- Is manifested before the person attains age twenty-two.
- Is likely to continue indefinitely.
- Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self sufficiency.

and

- Reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated.

Source: *The Developmental Disabilities Act of 1984* (P.L. 98-527, Section 102).

Governor's Planning Council on Developmental Disabilities has used three prevalence rates to estimate an answer. Based on the estimated 1985 Minnesota population of 4,193,000 the following figures were obtained:

Prevalence Rate	People With Developmental Disabilities
[redacted]	
[redacted]	
[redacted]	

The New Way of Thinking Starts From a Different Perspective

People with developmental disabilities are, first and foremost, people with ability. Without special assistance some people with developmental disabilities cannot take advantage of the freedoms and opportunities of our society. They are, however, fundamentally more like the rest of the population than they are different from it.

People with developmental disabilities have special needs, but their basic needs are the same. Funding, policies and services often have been focused only at the special needs of people with developmental disabilities. The result has been that their basic needs have gone unmet.

We have learned that services are most successful when basic needs are met in the context of addressing special needs. People with developmental disabilities, like all people, need:

- To be seen, first of all, as people.
- To experience love and friendship.
- To experience continuity in their lives, especially in relation to the people who are important to them.
- To be respected and treated with dignity.
- To have access to opportunities and information, to make choices and to exercise their rights.
- To learn those skills which are needed to participate, as much as possible, as valued members of their community.
- To have a decent and appropriate place to live.
- To have meaningful employment and contribute to the community.
- To have opportunities to continue to learn throughout their lives.

In response to these basic needs, our hopes for the future and our thoughts about the quality of our lives are often concerned with three basic issues—HAVING A HOME, not just a roof over our heads; LEARNING skills which are useful to our lives and careers, not just going to school; and WORKING, not just keeping busy. There is a fourth basic issue which gives vitality and fullness to our lives—DEVELOPING AND SUSTAINING RELATIONSHIPS with people who depend on us and upon whom we can depend.

A real home is a place to live the most personal moments of our lives. A home provides security and comfort, allows us to make choices and express ourselves. The people who share our homes are usually the people with whom we choose to spend time, be ourselves and feel close.

Real learning is lifelong. It means learning to understand ourselves. Learning involves developing skills which are useful to us both as individuals and as members of communities. The people with whom we learn are also teachers. Many become friends we can count on throughout our lives.

Real work means earning a living, being productive and making a contribution to our community. The relationships we develop with the people with whom we work are important to us.

Having a home, learning and working—each involves us as members of a community who both receive the support of others and make contributions to the community. Each involves us in the continuing process of individual growth and expression. Each involves us in developing relationships.

Having a real friend means being involved with someone who chooses to spend time with you just because they want to and not because they are paid to do so. Real friends broaden our opportunities and enrich our lives. Real friends are hard to find. It takes most of us a long time through contact with many different people to find that small group of friends who really matter. Opportunities that lead to friendships are essential.

People with developmental disabilities often are more handicapped by the environment than by their disabilities. Historically, our thinking and actions have focused on the ***in*** abilities of people with developmental disabilities. The concern was with "fixing the person" or "curing the deficit." Over time that focus has shifted to building on ***cap*** abilities and assisting individuals to develop and use their abilities.

The most dramatic shift in our way of thinking is the recognition that the social and physical environments are often a greater issue than abilities and disabilities. This is especially true in considering the expectations others have of people with developmental disabilities, and what people do based on those expectations.

Shirley Jennings is 42 years old.

She has lived in state institutions most of her life. Shirley has severe spasticity in all of her limbs. She was considered unable to communicate until she met the bioengineering team from the Association for Retarded Citizens—United States (ARC-US). Now with a computer, Shirley for the first time in her life is able to activate parts of her environment with sounds. By uttering the following sounds she creates enjoyable activities for herself:

"Four" —stories read on a videotape.
"Bee" —three different sequences of her family presented on videotape.
"Move"—a massage pad is activated.
"Ray" —a radio is turned on so she can enjoy her favorite music.
"Off" —she can turn all activities off.

The sense of accomplishment and enjoyment Shirley is experiencing through this technology is clear from her joyful facial expressions. Soon she will be moving out of the institution and into a small residence in the community. Her home will be designed so Shirley can control her environment. Shirley's story is available on a videotape, "New Horizons," from ARC-US (Cavalier and Brown, 1986).

We have made great advances in bringing very sophisticated technology to bear on the lives of people with disabilities. People who have trouble speaking were often unable to interact with others because of the low level of technology put at their disposal. People who had trouble moving their hands simply could not use sign language to their advantage. In a very short period of time, we have moved from manual spelling boards to laptop computers to synthesized speech to gaze activated computers.

The new way of thinking about developmental disabilities emphasizes supporting individuals, families, and communities. This support has several dimensions:

- Basing the provision of services on the informed choices, strengths and needs of individuals with developmental disabilities and their families, rather than forcing them to choose among a narrow range of pre-set options and approaches.
- Planning and providing services based on what people need and the abilities they have, rather than providing more services than are needed, or not providing those services which are needed.
- Supporting the individual, family and community members to gain access to the resources available in the community—jobs, houses, relationships with families, friends and associates —rather than replacing those resources with places populated only by professionals and other people with disabilities.
- Coordinating services and supports around the life of the individual rather than around the needs of staff and services.
- Recognizing the abilities of ordinary citizens—children, coworkers, neighbors—to teach people skills, assist them to participate and contribute, model appropriate behaviors, and develop relationships.

We have learned that all of these advances are possible. We have learned that when they are accomplished the quality of life experienced by all citizens is improved.

A NEW PERSPECTIVE ON *Policy*

An overview of the history of changes in services to people with developmental disabilities provides a context for considering an emerging policy perspective. In the 1800s thinking about developmental disabilities was marked by the concept of benevolent shelter. The eugenics movement in the United States during the early 1900s contributed to thinking of people with developmental disabilities as "defectives" and "deviants" who should be separated from community life (Wolfensberger, 1975). Thinking about developmental disabilities in these terms resulted in a centralized approach under which all residential, educational, work opportunity and other services were provided by institutions. In Minnesota and all other states, large state hospitals were constructed to deliver publicly supported services to people with developmental disabilities.

Beginning in the 1950s, expanding knowledge about the causes of developmental disabilities, new training/treatment programs, the civil rights movement and other factors began to change the thinking about developmental disabilities. The change in thinking about developmental disabilities was characterized by such themes as right to treatment, least restrictive environment, due process and human dignity. The policy response to this way of thinking called for "deinstitutionalization" and provision of community residential, educational and vocational services.

In Minnesota the shift toward a community orientation of services resulted in the construction of Intermediate Care Facilities for People with Mental Retardation (ICFs/MR), mandated special education classes in public schools and created developmental achievement centers (DACs), work activity centers (WACs) and other community agencies to provide day programs. Community services have succeeded in placing people with developmental disabilities in local communities, but have had less success integrating them into community life.

The new way of thinking about individuals focuses on outcomes: living in real homes, learning in regular schools and working in real jobs. These outcomes are to be achieved through support services provided on an individual basis. Implementation of policies derived from the individual approach to services has resulted in a new set of residential, educational and employment alternatives. Individual residential supports in Minnesota include the Family Subsidy Program, the Home and Community Based Waiver, Foster Care, Semi-Independent Living Services (SILS) and other arrangements. Individualized Education Programs (IEPs) and other provisions in the Education for All Handicapped Children Act (P.L. 94-142) characterize the implementation of this approach within the educational sphere. Work opportunities which have resulted from the individual approach to services include supported employment, transitional employment and competitive employment.

Each of the policy approaches—institutional, community oriented and individualized—has resulted in distinctive types of facilities, services and supports. The following milestones mark changes from an institutional to community to an individualized approach to service delivery during the past 30 years.

Thirty-five years ago parents revolted and protested the neglect and exclusion of their children with mental retardation. The most significant progress since that time has been the emergence of individuals with mental retardation as persons in their own right, as fellow human beings claiming their place in our society (Dybwad, 1985).

1957—Special Education for Handicapped Children (M.S. 120.17)—The Minnesota special education law requiring public school districts to provide special instruction and services for children with certain disabilities.

1963—The President's Panel on Mental Retardation—Presented a national plan that recommended community based care and a reduction of the number of people living in large, congregate care facilities.

1963—Mental Retardation Facilities and Community Mental Health Centers Construction Act (P.L. 88-164)—Provided financial aid for building community based facilities for people with mental retardation and people with mental illness.

1963—Social Security Amendments of 1963 (P.L. 88-156)—Established the Maternal and Child Health Program to improve prenatal care to high risk women from low income families. This was part of the legislative package designed by the Kennedy administration in response to the President's Panel on Mental Retardation.

1963—Minnesota Statute 252.21—Authorized the Department of Public Welfare to turn the Developmental Achievement Center Pilot Project begun in 1961 into permanent community services for people with developmental disabilities who were not served by the 1957 special education law.

1965—Vocational Rehabilitation Act Amendments (P.L. 89-333)—Mandated that services be provided for people with severe disabilities; allowed more flexible guidelines to permit extended evaluation periods for persons with mental retardation or other similar disabilities.

1965—Social Security Act Amendments (P.L. 89-97)—Established Medicare/Medicaid, recipients of Aid to the Permanently and Totally Disabled (about 15% of whom were persons with mental retardation) were made Medicaid eligible.

1967—Social Security Act Amendments (P.L. 90-248)—Introduced the concept of Intermediate Care Facilities for persons not needing skilled nursing care.

1967—Mental Retardation Amendments of 1967 (P.L. 90-170)—Congress appropriated grants for short term staffing of community facilities for people with mental retardation.

1970—Urban Mass Transportation Act Amendments (P.L. 91-453)—Required local governments to plan and design mass transportation facilities and services to be accessible to people who were elderly and/or handicapped.

1970—The Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517)—Extended and modified P.L. 88-164 to cover developmental disabilities other than mental retardation; authorized a flexible state formula grant for planning, construction, and services; required every state to establish a governor's council on developmental disabilities; and provided "core support" for University Affiliated Facilities.

1971—***Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania***—Landmark decision which affirmed the right to education at public expense and due process for children with disabilities.

1972—Social Security Amendments (P.L. 92-223)—Authorized use of Medicaid funds to pay for care of persons residing in public residential facilities for people with mental retardation or "related disabilities" if federal standards are met.

1971—Special Education Amendments (M.S. 120.03)—Minnesota expanded its special education law to include services to children with severe handicaps (so-called "trainable mentally retarded").

1972—***Wyatt v. Stickney***—A precedent-setting Alabama class action suit in which a federal district court set forth the constitutional right to treatment and rehabilitation in the least restrictive environment.

1972—Social Security Act Amendments (P.L. 92-603)—Established Supplemental Security Income to standardize assistance programs to aged and disabled people in need, including those with developmental disabilities, effective January 1, 1974.

1973—Rehabilitation Act of 1973 (P.L. 93-112, Section 504)—This act increased the amount authorized under the Rehabilitation Act of 1921 to over one billion dollars for training and placement of people with mental and physical handicaps into employment. The act made explicit Congressional intent that vocational rehabilitation services be made available to people with severe disabilities. Section 504 prohibited discrimination based on disability. This act has provided the legal basis for many anti-discrimination lawsuits involving the rights of people with disabilities.

1974—***Welsch v. Likins***—A federal district court in Minnesota ruled that residents of Cambridge State Hospital had a constitutional right to treatment and care in the least restrictive environment.

1974—Housing and Community Development Act of 1974 (P.L. 93-383)—Authorized Community Development Block Grants which were a major source of federal aid for removing architectural barriers and providing rent subsidies.

1974—***United States v. Solomon*** (State of Maryland)—The first class action suit filed by the United States Department of Justice on behalf of people with mental retardation in institutions to ensure they receive treatment.

1974—Executive Order 11776—President Nixon reaffirmed the 1971 national goal of returning one-third of the 200,000 residents with mental retardation in institutions to community settings.

1975—***New York Association for Retarded Citizens v. Carey*** (Willowbrook)—The United States District Court in Brooklyn reaffirmed the constitutional right to treatment in the least restrictive setting and most normal living conditions possible. The basis for the ruling was the Eighth Amendment.

1975—Education for All Handicapped Children Act (P.L. 94-142)—Mandated free, appropriate public education in the least restrictive environment. Individualized Education Programs (IEPs) were mandated with special education and related services designed to meet the unique, individual needs of each child.

1975—Developmental Disabilities Assistance and Bill of Rights Act (P.L. 94-103)—This major amendment to P.L. 91-517 mandated a Bill of Rights for people with developmental disabilities and required that by October 1, 1977 every state establish a protection and advocacy system as a condition for receiving state formula grant funds.

1975—Minnesota Statute 252.28—Established zoning for group homes of six or fewer as single-family residences and homes with seven to sixteen for multi-family use.

1975—***Anderson v. City of Shoreview***—A Minnesota court upheld the granting of a special permit for construction of group homes over the objections of neighboring homeowners.

1976—Family Subsidy Program (M.S. 252.37)—Provided subsidies to families for support of children with developmental disabilities to live in the natural family home.

1977—***Pennsylvania Association for Retarded Citizens v. Penn-hurst School and State Hospital***—A Federal Court ruled that keeping people with mental retardation in institutions, isolated from society, is a violation of their Fourteenth Amendment constitutional rights to equal protection.

1978—Rehabilitation Comprehensive Services and Developmental Disabilities Act (P.L. 95-602)—Defined developmental disabilities in functional terms and identified priority areas for Council activities.

1979—Minnesota Community Social Services Act (CSSA, M.S. 256E and Rule 30 [9525.1200])—Mandated county authority over the funding, planning and administration of community social services. County boards were made responsible for: 1) an assessment of the needs of each person applying for services; 2) protection for safety, health and well-being of individuals; and 3) a means of facilitating access to appropriate services for people with disabilities.

1980—***Welsch*** Consent Decree—Signed in U.S. District Court requiring the State of Minnesota to: 1) substantially reduce the number of people with mental retardation in regional centers to 1,850 by 1987; 2) improve overall conditions and staff/resident ratios; and 3) develop community services for people with mental retardation released from regional centers.

1980—Social Security Amendments (P.L. 96-265—Section 1619 and b)—Breakthrough amendments for people with developmental disabilities to support a special three-year demonstration project which allowed benefits to continue for disabled recipients engaged in paid employment.

1981—Omnibus Reconciliation Act (P.L. 97-35, Section 2176, "Home and Community Based Waiver")—Allowed states for the first time to finance a wide array of community services through Medicaid by waiving regulations. The waiver has helped to prevent admissions and reduce populations in ICF/MR facilities.

1981—Vulnerable Adult Protection Act (M.S. 626.557)—This Minnesota law gave special protection to adults against abuse and neglect, and mandated reports by professionals and employees of suspected cases.

1981—Case Management for Persons with Mental Retardation (M.S. 256B.092, "Rule 185")—Mandated county case management of services for people with mental retardation and required a needs assessment, an individual service plan, and ongoing support.

1982—***Duane Youngberg et. al., Petitioners v. Nicholas Romeo***—United States Supreme Court ruled that Romeo had the right to treatment while involuntarily deprived of liberty at Pennhurst.

1982—Social Security Amendments (P.L. 97-248, "Katie Beckett Amendments")—Permitted states to use Medicaid for certain children with disabilities who were 18 years of age or younger, living at home, and who would be eligible for Supplemental Security Income (SSI) if they were institutionalized.

1983—Education Amendments of 1983 (P.L. 98-199)—Established and funded services to facilitate the transition of students with disabilities moving from school to the community and/or work settings.

1983—Semi-Independent Living Services (M.S. 252.275, "SILS")—First grants made available to counties in Minnesota to provide Semi-Independent Living Services to reduce the number of people with developmental disabilities in ICF/MR facilities.

1983—M.S. 265B.501—Changed Developmental Achievement Center funding so Medical Assistance and Waiver funds could be used for day programming.

1983—Moratorium on Intermediate Care Facilities for the Mentally Retarded (M.S. 252.291)—Required the total certified ICF-MR capacity not to exceed 7,500 beds on July 1, 1983 and 7,000 beds on July 1, 1986.

1984—Carl Perkins Vocational Technical Education Act (P.L. 98-524)—Mandated development of quality vocational education programs and expansion of existing programs with a 10 percent "set aside" to support programs for individuals with disabilities.

1984—Child Abuse Amendments (P.L. 98-457)—Mandated reporting of medical neglect if treatment is withheld from infants with disabilities. This was the Congressional response to the "Baby Doe" decision.

1985—Minnesota Statute 120.17—Mandated the lowering of the age of eligibility from 4 to 3, effective September 1986, for public school special education services to young children with special needs and required the establishment of Interagency Early Learning Committees at the local level.

1985—Other Related Conditions Bill (M.S. 252.27)—Revised the out of date language of statutes concerning persons with mental illness and persons with mental retardation. Defined "Other Related Conditions" to recognize autism, cerebral palsy, and epilepsy and used a functional definition.

1985—Interagency Office of Transition Services (M.S. 120.183)—Established transition services in the Minnesota Department of Education for students moving from school to work and community living.

1986—Amendments to the Education of the Handicapped Act (EHA, P.L. 99-457)—Mandated preschool programs for three to five year olds and planning for early intervention programs for infants and toddlers with disabilities.

1986—Rehabilitation Act Amendments (P.L. 99-506)—Established a new state grant program for supported employment for people with severe disabilities. It also revises eligibility criteria for the Basic State Vocational Rehabilitation program, allowing more people with severe disabilities to become eligible and receive services.

1986—Employment Opportunities for Disabled Americans Act (P.L. 99-643)—Made permanent the Section 1619 (a) and (b) incentive program of the Social Security Act for Supplemental Security Income recipients. The program allows people to work and maintain their SSI eligibility and medical coverage under Medicaid.

A NEW WAY OF *Learning*

In our society, learning is a valued activity, important to the development of individuals. Growth, learning and belonging are important to all children, but especially to children with developmental disabilities. If these children are to participate and contribute to their communities, it is essential that their education be efficient and effective. Many children with developmental disabilities have difficulty learning. It is critical that we develop strategies and approaches to prepare children for life and enhance their individual capabilites.

Historically, the changes in our thinking about education have paralleled, and in some cases determined, our thinking about other areas of life. When the institutional approach prevailed, young people with developmental disabilities did not attend public schools; they stayed at home, were admitted to state institutions, or attended special, private schools. A shift from this prevailing practice took place in Minnesota in 1957 with the passage of the Special Education for Handicapped Children law (M.S. 120.17). The law required all school districts to provide special education services to children whose IQs were above 50. The provision of services was made optional to children with more severe or untestable levels of disability. In response to the resulting lack of educational opportunities for children with severe disabilities, Developmental Achievement Centers (DACs) began providing educational services to these children (and to adults) on a pilot basis in 1961, and on a permanent basis in 1963.

In 1971, public school special education services were mandated in Minnesota for **all** children with disabilities. As a result of this amendment to Minnesota's special education statute, most special education services were offered in separate classes in regular schools or in special schools within local districts during the early 1970s.

Federal legislation (P.L. 94-142), passed in 1975, shifted emphasis in Minnesota from one of getting children with disabilities into schools to an emphasis on the nature of the education they receive. Federal education policy supported the concept of individualized, outcome-oriented learning experiences for all children with disabilities. Minnesota's educational services to children with disabilities reveals both changes in the way we do things and emerging needs and issues. The following sections summarize current educational services from preschool to adult vocational programs.

The Education for All Handicapped Children Act (P.L. 94-142) requires each state to provide educational services consistent with the following major guidelines:

- **FREE AND APPROPRIATE EDUCATION:** Public schools must identify all students with disabilities within their geographic areas and provide free instructional and support services to meet each student's unique educational needs.
- **INDIVIDUALIZED:** Public schools must recognize that each learner is unique and has a right to an education which is tailored to individual strengths and needs.
- **INTEGRATED SETTING:** To the maximum extent appropriate, children with disabilities are to be educated with children who are not disabled. Special classes are to occur only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.
- **DUE PROCESS:** Parents or guardians must be provided with prior written notice of actions which might affect the status of their child. If disagreements cannot be resolved through conciliation conferences, a due process hearing must be conducted with both sides represented before an impartial hearing officer.

Cory, left, and Dan go to the Special Friends program at Canal View School in Rosslyn.

The role of the family is not an educational extension of the intervention program. Rather, the opposite is true, the intervention program should be an extension of the family....(Wright, Granger, and Sameroff, 1984).

Early Childhood—Birth Through Age Five

Early childhood is a time when growth, learning and belonging are critical issues. The stimulation and learning that take place in the first two years of life are critical to child growth and development. The absence of stimulation and learning during this period has lifelong consequences. It is also the time when families develop the basis for their ongoing relationships and children learn about play and friendship. The quality of infant care and stimulation depends on the knowledge and skills of parents, guardians and others caring for the child.

In Minnesota, four public agencies are involved in providing early intervention and early childhood family education programs. The Department of Health provides Services for Children with Handicaps, Maternal and Child Health, Early and Periodic Screening, Community Health Services and Public Health Nursing Services. The Department of Human Services provides Early and Periodic Screening, Diagnosis and Treatment; Developmental Achievement Centers; day care and nursery programs; and case management. The Department of Jobs and Training supports Head Start programs. The Department of Education offers Preschool Screening, Early Childhood Special Education, Early Childhood Family Education, and Community Education. To ensure that the early intervention and education services provided by these state agencies are coordinated, the 1985 Legislature required all school districts to provide leadership in Interagency Early Learning Committees.

The Early Childhood Special Education services of the Department of Education are most directly linked to the integration of services for children prior to their entry into regular school programs. In 1967, Minnesota passed permissive legislation allowing school districts to serve preschool children with disabilities and receive full state aid. The importance of preschool education was further recognized in Minnesota in 1985 (M.S. 120.17) and by Congress in 1986 (P.L. 99-457) by mandating education for all children with disabilities from age 3 to 21. The legislative agendas of advocacy groups in Minnesota continue to place a high priority on achieving mandated services and education for children from birth.

Preschool programs are delivered directly by school districts or indirectly through contracts with other districts or agencies such as Developmental Achievement Centers. The services may be provided in the home, in a center or through consultative arrangements. The common theme of early special education programs stresses parents or principal caregivers as the child's primary teacher.

Table 1 depicts the extent of participation in preschool special education programs in Minnesota. In total, 8,660 children from birth through age five received such services in 1985. They represent 10.6 precent of all children receiving special education services during that year. Just over one half (52 percent) of Minnesota school districts opted under permissive legislation to provide services to 514 children from birth to two years of age during 1985. The Minnesota State Department of Education estimates there are approximately 1,500 children in this age group who are eligible for services, but are not currently receiving public school services.

The total cost of preschool special education services in 1985 was $15,069,000. Local sources provided 26 percent of the funds, state sources provided 60 percent and 14 percent came from the federal government. Cost-benefit studies demonstrate this is a wise use of resources. For each dollar invested in preschool education, a savings of $4.75 is achieved in lower special education costs, reduced welfare payments, and higher worker productivity (Weikart, 1983).

Number of Preschool Age Children with Special Needs Served in Minnesota Public School Special Education Programs and Under Contracts with Other Agencies, 1985.

Table 1

Age	Children Served	Percent
[illegible]	[illegible]	[illegible]
Total	[illegible]	100

Source: Minnesota Department of Education, 1985.

With the advent of P.L. 94-142 there is a great need for parents to know how to use the empowerment they have under this legislation (Betty Pendler, parent).

Students Served (ages 6-21), Expenditures and State and Federal Aids Paid by Special Education Program Area in Minnesota During Fiscal Year 1983-84

Table 2

Program Area	Students Served (unduplicated count) Number	Percent	Total Expenditures (thousands) Amount	Percent	State and Federal Aids Paid (thousands) Amount	Percent
Speech Handicapped	19,163	24.2	$ 20,219	10	$ 14,667	10
Educable Mental Retardation	9,676	12.2	25,198	13	17,612	13
Trainable Mental Retardation	3,713	4.7	24,727	12	16,375	12
Physically Handicapped	1,349	1.7	6,678	3	4,776	3
Hearing Impaired	1,724	2.2	5,656	3	4,116	3
Visually Handicapped	441	.6	1,551	1	1,081	1
Special Learning Disabilities	35,644	44.9	63,145	32	44,309	31
Emotionally Disturbed	6,774	8.5	21,662	11	14,237	10
Deaf and Blind	28	.1	30,397	15	23,503	17
Health Impaired	826	1.0				

Source: Minnesota Department of Education, 1985

The challenge today is to take what we have learned from the special programs and begin to transfer this knowledge to the regular classroom (Will, 1986).

The School Years—Kindergarten Through Grade 12

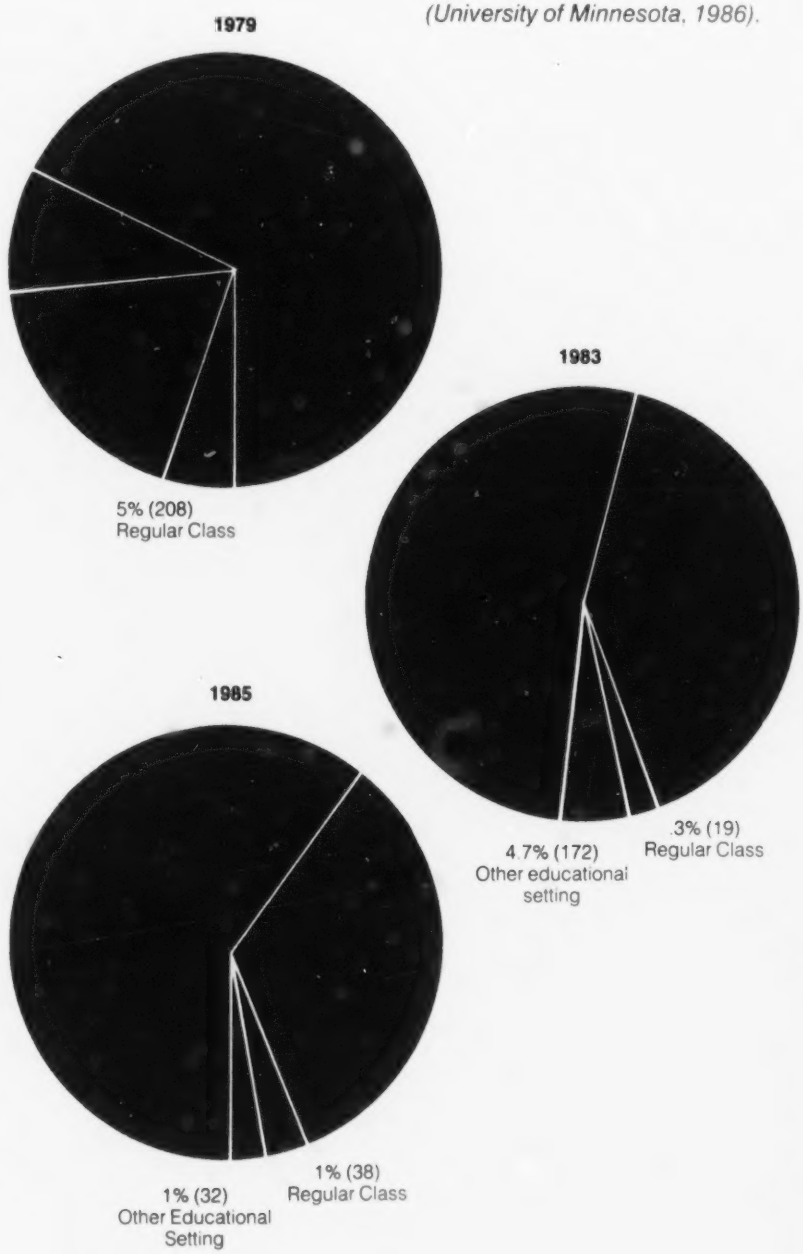
In fiscal year 1984, over 699,000 students were enrolled in Minnesota public schools. Special education services were provided to 10.3 percent of these students (excluding children under the age of six years). Table 2 summarizes the extent of services, total expenditures, and state and federal aid in Minnesota for 1984. The special education categorical aids during 1984 were $140,676,000 from state and federal sources. The largest group of students defined by a diagnostic category for receiving special education services was "special learning disabilities" (SLD) representing 45 percent of the students and 32 percent of the expenditures.

Most of the students receiving special education services in the public schools are not developmentally disabled according to the federal definition. Students likely to meet the definition of developmental disabilities are those diagnosed as "trainable mentally handicapped" (including moderate, severe and profound mental retardation), physically handicapped, emotionally disturbed, deaf and blind and autistic.

The emphasis of both policy and legislation is on integration of students with disabilities into regular classroom settings and local schools. Minnesota students with severe disabilities, however, for the most part were served in separate classrooms and buildings during 1985 (see Figure 1).

Numbers of Students with Moderate and Severe Mental Retardation and Their Educational Settings on December 1, 1979, December 1, 1983, and December 1, 1985.

Figure 1



Source: Minnesota Department of Education, 1985

Fifty-one percent of parents surveyed in a recent transition study reported that IEP goals and objectives related to the post school needs of their son/daughter were not being discussed with them (University of Minnesota, 1986).

Results of a recent study on transition point out several concerns regarding the post school experiences of youth with disabilities. Nine percent of former students with moderate or severe handicaps have full-time paid employment; another 32 percent have part-time employment (University of Minnesota, 1986).

Special Vocational Training—Secondary Students and Adults

In addition to the primary concern of integration, a second area of concern is preparing students with developmental disabilities for the adult world. The term transition describes the change from secondary education to post secondary education or employment and community living. In recognition of this change, the Minnesota Legislature established an Office of Transition which is responsible for data collection, coordination and providing information, consultation and technical assistance to state and local agencies involved in transition services. In addition to providing workshops on transition, a state interagency agreement to cooperate in providing transition services was established. There are nine agencies involved in planning for the approximately 4,000 students with disabilities who leave school annually (Minnesota Department of Education, 1986).

Vocational education and training are part of the transition process which prepare secondary and post-secondary students for productive activity following school. Public school districts are required to make available 560 hours of vocationally oriented instruction in two or more curriculum areas to **all** secondary students—including students with disabilities. Local districts may provide these services or arrange them through cooperatives. In 1985, there were 35 joint power vocational training centers providing vocational training for students beginning in the tenth grade. During that year the total secondary vocational program expenditures for students with special needs were $6,080,000.

Very few of the 9,000 (duplicated count) students with special needs involved in these programs would meet the federal definition of developmental disabilities. Instead, these students would be considered to have mild or moderate disabilities. In 1985, these special vocational students received services integrated with regular students. Resources were used to hire work experience coordinators, support service managers and paraprofessional aides.

Public post-secondary vocational education is provided in Area Vocational Technical Institutes (AVTIs) operated under the jurisdiction of the State Board for Vocational Technical Education. AVTIs have 40 specially designed, community-based programs offering vocational or occupational skills training for students with disabilities. The programs are similar to those provided in regular secondary vocational education, but there are more training opportunities. Again, participating students would not meet the federal definition of developmental disabilities.

A new approach to vocational education which does include young people who meet the definition of developmental disabilities was developed in 1986 through a cooperative agreement sponsored by the Metropolitan Council's Developmental Disabilities Program. The Governor's Planning Council on Developmental Disabilities provided a grant to the Metropolitan Council for the development of a Community Employment Training Program for adults with developmental disabilities. As a result, a pilot interagency agreement between several public and private agencies was established. The coordinated effort involved a training institution (the Northeast Metro Technical Institute); a coordinating agency (the Metropolitan Council); a planning and funding agency (the Division of Rehabilitation Services); two agencies providing training and supervision (Cerebral Palsy Work Activity Center now called Access Ability and Midway Training Services, Inc.); and an employer (Consul Corporation and two of its Chi Chi's Mexican Restaurants). Through this agreement, 359 hours of on-the-job training were provided to 16 individuals with severe disabilities from the developmental achievement center. As of June, 1986, 8 of the 16 people were permanently employed, and 8 individuals were waiting for job openings at the two restaurants or elsewhere. The approach is being replicated in Willmar and Pine City.

Components of a Functional Curriculum

There is considerable knowledge about what is required to plan, implement and evaluate an individualized and functionally oriented education for students with disabilities. This new way of thinking about learning and belonging is well articulated. The following examples identify some of the components of a quality education based in part on criteria described by Donnellan (1986).

- **The content, style, people, objectives and places of education must be age appropriate and individualized.** Students with developmental disabilities often cannot learn all of the skills which can be learned by non-handicapped people of the same age. At the same time, it is inappropriate to offer programs which are geared to significantly younger students. The goal is to minimize the differences in performance of people with developmental disabilities and their peers. Instructional materials, peer interactions, learning objectives and service locations all must be chronologically age appropriate. Young adults do not play with wooden puzzles or sing nursery rhymes.

Age-Inappropriate Materials for Young Adults Identified During a Site Visit:

- Kitty Puppy Puzzle
- Fat Albert Puzzle
- Candyland—A Child's First Toy
- Ring Toss

(Luther Granquist, Attorney, Legal Advocacy for Developmentally Disabled Persons)

The first generation of students served by P.L. 94-142 are now graduating and their parents have higher expectations than earlier generations of parents. It is unlikely that parents and caregivers who have invested heavily in children's services will be satisfied with an adult service system that can only produce a 20 percent employment level or a service system in which 80 percent of the recipients will be living below the poverty line one year after separation from high school (Fifield and Smith, 1985).

Parents and professionals felt strongly that it was very important to prepare students for future adult life activities such as employment, community living, and citizenship. Overall, however, these groups felt that schools were doing only moderately well in these areas (University of Minnesota, 1986).

- **The goals, objectives and activities of education must be functional.** People with developmental disabilities need to learn things that are truly useful to them. The functional aspects of skills related to working, for instance, can be assessed by asking, "Would someone be paid to do this?" People do not get paid to stack rings or match colors. As an example, students could be taught to sort knives, forks and spoons instead of learning to sort colored tiles.
- **Interactions with nonhandicapped peers and others, are essential.** The Education for All Handicapped Children Act (P.L. 94-142) requires that students be educated with nonhandicapped students to the "maximum extent appropriate." It is not only appropriate, but essential to ensure that people with developmental disabilities have a wide variety of opportunities to interact with peers and others who are not disabled. Education should involve a variety of such opportunities at school and away from school. The more constructive, comprehensive and long lasting the interactions the better—the development of mutual respect and interest takes time.
- **A variety of people and instructional arrangements need to be involved.** People with developmental disabilities need to learn how to interact with people other than teachers and how to use skills in a variety of settings. This means that activities should be designed to enable interaction with a wide variety of people. Programs which facilitate learning functional skills in a variety of environments are more appropriate than programs which confine learning to single environments. People learn skills best in the natural places where they happen. For example, bedmaking should be taught in the home and grooming should be taught in the locker room or a dressing room, not a classroom.
- **Highly individualized adaptations must be made.** Many students with developmental disabilities will not be able to participate in a variety of situations and environments unless specialized and individualized adaptations are made. These adaptations include alternate ways of communicating, changing the order in which things are accomplished and modifying the setting. A person learning to read who is unable to turn the pages should be provided with a page turning device.
- **Preparing for the future is critical.** Parents and educators need to focus on how and where the student will function as an adult and gear learning activities toward the actual work and living arrangement the person will experience. Students with disabilities who will live on their own must learn cooking, shopping and other skills leading to self-reliance.

My body makes me disabled; society makes me handicapped. (Anonymous)

Fifty-two percent of the parents in a recent transition study communicated that they were not familiar with the types of community services available for their son-daughter following graduation from school. There was no clear consensus on whether the school, the service agencies or both should be responsible for collecting and sharing this information (University of Minnesota, 1986).

A staff person from an advocacy organization asked 20 children in a special education classroom, "What do you want to do when you grow up?" ***None*** *of the children could answer the question. They had no idea what it meant to be a productive member of society.*

New Directions in Special Education

Federal and state policies and funding have bolstered significantly the presence of students with developmental disabilities in Minnesota's school systems. There is little information, however, to indicate whether these students are receiving an education which prepares them for life. A recent monitoring report by the federal Office of Special Education Programs, however, indicated that in Minnesota the effort to provide special education in our schools has resulted in **decreased** integration of students with developmental disabilities (U.S. Department of Education, 1985). The fact is that many administrative and funding arrangements have resulted in separate schools and classes. This creates segregation, not integration.

More attention is needed in the areas of **Integration,** the implementation of a **functional curriculum** and **transition services** from school to adult life. Taxing authority and categorical aids that serve as disincentives to integration in regular schools and classes need to be changed. The policy of "least restrictive environment" calls for the presence and participation of students with developmental disabilities with other students. Isolating either group denies opportunities to learn from one another, to observe role models and to cultivate a broader range of social relationships and attachments.

Many students with developmental disabilities have trouble learning some skills and then generalizing what they learn to other settings. For some, there may be things they will never be able to learn, but there are ways of adapting the environment to compensate for a lack of knowledge or a particular skill. For these reasons, it is critical that the curriculum provided for students with developmental disabilities be functional and relate to a real community.

Traditionally, the curriculum has been patterned on academic objectives for all students with lowered expectations and increased time allocations for students with developmental disabilities. Emphasis has been placed on learning basic reading, writing and arithmetic skills. The functional approach, on the other hand, determines which skills and what knowledge would make the student more able to function in the community (at home, at work, at leisure and participating in the community), then teaching those skills in the settings where they would be used. A clear example of this can be found in vocational skills which are most effectively taught in real places of work. With this approach, attention is paid to the skills a student is likely to learn. When it is unlikely that a skill will be learned as taught, adaptations (technological aids, procedures, personal assistance) are provided in the environment so the individual can achieve the function.

This approach does not assume that students with developmental disabilities cannot or should not learn to read, write or do arithmetic. It does, however, assume that these skills are not necessarily essential for living, working and participating in the community. Given the relatively short period of time spent by a student in school, it is important to focus on skills, relationships and knowledge that will be most useful, and to learn about the ways environments can be adapted to compensate for skills and knowledge students are not able to acquire.

A NEW WAY OF *Living*

In Minnesota, there is a growing recognition that having a real home is as important to people with developmental disabilities as it is for everyone else. For children, home means parents or guardians who build an atmosphere of love, affection, security, and comfort. For all of us, home means moral and material security and a place to invite friends.

The gradual recognition that real homes are important to people with developmental disabilities has led to significant policy shifts in residential services in Minnesota:

- Efforts to reduce the numbers of people with developmental disabilities in regional centers and other large facilities, and to increase the resources available for community options.
- Efforts to increase the support available to individuals and families so people with developmental disabilities can maintain their homes in the community.

Returning People to Communities

The trend toward deinstitutionalization began in the 1960s. Prior to that time, the prevailing practice was to admit both children and adults with developmental disabilities to regional centers on an indefinite basis. Over the last fifteen years efforts have focused on preventing out-of-home placement and moving children from regional centers to less restrictive settings. The average age of first admission to institutions in the United States has risen from 10.4 years in the 1960s to 21 years in 1985. Between 1977 and 1982, there were 30,000 fewer children (birth-21 years) in out-of-home placements.

The Education for All Handicapped Children Act (P.L. 94-142) has had a dramatic effect on reducing the number of children with developmental disabilities in out-of-home placements. P.L. 94-142 guaranteed the right of all children with disabilities to receive an education. It also enabled families to be relieved of responsibilities during the day, thus assisting them to better support their children at home. As of November, 1986, there were 28 children with developmental disabilities in the regional centers in Minnesota.

In 1960, there were 6,008 Minnesotans with developmental disabilities in regional centers, the largest number in Minnesota history (Minnesota State Planning Agency, 1985). In 1986, there was an average daily population of 1,868 people with developmental disabilities in the state's seven regional centers in Fergus Falls, Brainerd, Moose Lake, Cambridge, Willmar, St. Peter, and Faribault.

According to Braddock et al. (1986), the number of residents in regional centers has declined between 1977 and 1986 from an average daily population of 3,085 to 1,868. During the same time period, the actual operating costs have increased from $51,405,000 to $96,558,000. When adjusted for inflation, expenditures have remained about the same during this 39 percent decline in number of residents. The costs per day per resident have risen from $45.65 in 1977 to $158.20 in 1986.

Suzanne, left and Pam now live in a semi-independent living apartment together. They both previously lived in institutional situations.

The Development of Alternatives to Regional Centers

In order to reduce the number of people residing in regional centers and to prevent their admission, alternative residential services have been developed in Minnesota. Most of these alternatives have involved the use of federal Medicaid dollars for community ICF/MR facilities or Medicaid funding which has been "waivered" and redirected to more individual and family options. Some of the new alternatives have been supported by state and local funding, such as Family Subsidy and Semi-Independent Living Services.

Two major forces have contributed to the shift from an institutional approach regarding residential care to a community approach:

- The ***Welsch*** Case: The original court order established the right to treatment and placement in the least restrictive environment. The 1980 ***Welsch*** Consent Decree mandated a reduction in the number of people with mental retardation in regional centers from 2,650 to 1,850 over the period from 1980-1987.
- Title XIX Medicaid funds (1971) to stimulate the construction of ICF/MR facilities (P.L. 92-223): Minnesota developed more than thirty ICF/MR facilities per year in the 1970s in response to this provision.

Community ICF/MR facilities funded by Medicaid were the first alternative to regional centers in Minnesota. Today, there are 330 privately owned community ICF/MR facilities ranging in size from 6 to 165 residents. Of these, 278 serve fewer than 16 residents, and 52 serve 16 or more. In addition, regional centers have ICF/MR certified beds.

In 1983, the Minnesota Legislature placed a moratorium on new construction and expansion of ICF/MR beds. It also directed the Department of Human Services to reduce the number of combined beds in regional centers and community ICF/MR facilities from 7,500 to 7,000 by 1986. The moratorium was directly connected to the application for a Home and Community Based Waiver in Minnesota allowing Medicaid funds to be used for a wide range of supports with the exception of room and board. The savings accrued from not developing ICF/MR facilities and from reducing the number of ICF/MR beds has been used to fund waivered services. The moratorium, the decision to reduce the number of ICF/MR beds, and the use of the Home and Community Based Waiver all represent significant shifts in thinking.

Nursing homes represent another alternative to regional centers. They are not viewed, however, as an acceptable community placement for people with developmental disabilities under the age of 65 because they are not required to provide active treatment. The Department of Human Services estimates that 580 people with developmental disabilities under the age of 65 were living in nursing homes as of July, 1986.

Smaller, More Individualized Options

The individual approach to services in the community reflects a newer and still developing way of thinking about where people with developmental disabilities live. The emphasis is on promoting desirable outcomes through individualized planning and case management. The goal is not to "make a placement," but rather to flexibly design and manage a variety of settings and resources which will support the development of a real home. The emphasis is on using typical residential settings. Needed support might be minor or major and involve one or more of the following—a daily phone call or regular visit to the home, an access ramp or bathlift, special training for parents, periodic respite, or a live-in roommate or care provider. These supports are important and often critical. They do not, however, alter the desirable characteristics of a "home." They can be provided in typical houses as indicated in the following descriptions.

Supported Living Arrangements

Supported Living Arrangements (SLAs) provide habilitation services and supervision for up to 24 hours a day for people with developmental disabilities who need regular and/or specialized services. These services may be provided in the person's own home, a special foster home, or a small group home. Up to six adults or three children can be accommodated in an SLA. Regular housing is used as much as possible. Funding is provided under Foster Care or the Home and Community Based Waiver.

Foster Care

Foster care is provided by families who qualify and are licensed to provide homes for people with developmental disabilities. Foster families are reimbursed by the county on a monthly basis. As of September, 1986, there were 482 adults and 769 children with developmental disabilities receiving foster care in Minnesota, not including those individuals who were receiving waivered services. Many SLA services are provided in foster homes.

Foster care offers great potential for a real home—home-like size, choice and control. Much depends, however, on the interests and values of the foster parents. The involvement of the individual's natural family may or may not be possible. Foster homes may provide a very home-like arrangement, but monitoring is necessary because licensing standards do not guarantee the values and conditions of a real home. One notable difference between foster care and other residential services for people with developmental disabilities is that counties certify foster homes and enforce standards.

Semi-Independent Living Services

Semi-Independent Living Services (SILS) are intended for people who require less than 24 hours of supervision and are able to manage their own home with little assistance. A typical arrangement involves two to four adults in an apartment or house with supervision and needed services (counseling and training in self-care, shopping, cooking, cleaning and/or transportation) provided by a licensed agency. The primary goal of SILS is to promote independence and self-sufficiency with appropriate and necessary support and backup assistance.

SILS are funded by grants from the state to county boards combined with county Community Social Service Act dollars. In fiscal year 1986, the state contributed $2,620,800 (70 percent) and counties contributed $1,183,100 (30 percent). In 1986, the number of individuals who received SILS services averaged 830. People who use SILS and are not capable of full financial self-support may receive supplemental income from one or a combination of the following: Supplemental Security Income (SSI), Minnesota Supplemental Aid (MSA), Social Security, Housing and Urban Development Section 8, General Assistance (GA) and food stamps.

The Natural Family Home

More children with developmental disabilities live in natural family homes than all other arrangements combined. Most families with children who have developmental disabilities receive no public assistance. The Home and Community Based Waiver and the Family Subsidy Program do provide support to a limited number of families. These programs are intended to make family living possible for children who would otherwise require an out-of-home placement.

The Home and Community Based Waiver waives Medicaid regulations to encourage people to leave ICF/MR facilities and to prevent people from being placed out of the home into these facilities. Services involve case management, respite care, homemaker and in-home support services, supported living arrangements, day habilitation and minor adaptations to a house or apartment.

The reality is that less than one percent of all residential funds are used to support families—the people most often involved in providing a real home for people with developmental disabilities.

In order to qualify for waivered services a person must: 1) have a diagnosed developmental disability; 2) be eligible for Medicaid; 3) be a resident of an ICF/MR facility, or at risk of becoming a resident within one year if community support is not provided; and 4) have planned and documented needs for daily intervention. In 1986, the Minnesota Legislature limited the number of persons allowed to receive services under the waiver to 1,000. In 1986, the Division of Mental Retardation at the Minnesota Department of Human Services reported an average monthly caseload of 345 people receiving waivered services. Counties have received an allotment for waivered services and are in varying stages of planning for individuals to use the waiver funds.

Another type of individualized approach is the Family Subsidy Program—a cash grant to families to cover a portion of expenses for diagnostic assessment, homemaker services, training, special equipment, visiting nurses, therapists, preschool programs, related transportation, and/or parental relief or child care. The maximum allowance for each family is $250 per month or $3,000 per year. This state funded program is intended to assist families to maintain their children with developmental disabilities at home. During the first nine months of 1986, a monthly average of 255 families received family subsidies averaging $235 per month and 146 families were on a program waiting list as of September, 1986. Because of a fiscal crisis, the 1986 Legislature reduced the program budget for Family Subsidy to $709,000 in FY 1987 from $737,000 in FY 1986. At the same time, the upper limit of age eligibility was increased from 18 to 22 years.

New Ways of Developing Individualized Options

At the same time facilities and smaller community options have developed in Minnesota, we also have had increased experience with different ways of organizing the delivery of services. The idea of supporting families so their children can stay at home was a major change in thinking.

Five other methods of service delivery, each quite different, are also developing in Minnesota: case management; core cluster service delivery systems; consumer-owned housing; state operated community based programs; and centers for independent living.

Case management is necessary to broker and manage the process of delivering services to people with developmental disabilities. Counties are responsible for providing case management under Rule 185. The basic idea is that the system must work for the individual and the case manager's responsibility is to ensure that it does.

Core clusters provide a network of services that are programmatically and administratively linked to a "hub" or "core" residence within a geographic area. The cluster provides a full array of individualized living environments and other support services to individuals and their families. In Minnesota, an example of a core cluster arrangement is being developed by Adaptive Living, Inc. in Washington County.

Consumer-owned housing arrangements are a recent development in Canada, the Northeastern United States and Minnesota. Families or individuals with developmental disabilities buy or rent housing, and receive support services. Because an individual has a home, it is the services that change as individual needs change. In some cases substantial support is provided by neighbors. Formal services are involved in a supplemental way. The emphasis is on developing and supporting a home and neighborhood life for the individual by providing services as they are needed. A few Minnesota families have developed such arrangements for their sons and daughters. In Winnipeg, Canada 60 people living in 20 households belong to the Prairie Housing Co-operative. Twelve of the 60 people have disabilities.

State operated programs are designed to redirect regional center resources, personnel and residents into community based services. These programs are in a pilot stage operating through the regional centers at Cambridge and Faribault. The intent is to facilitate the transition of both residents and regional center employees to the community.

Centers for Independent Living were authorized by the Rehabilitation Act of 1973, and are funded by federal and state funds. They were created to provide services for people with disabilities so they can live and work more independently. Their primary function is to assist people through: peer counseling, housing assistance, accessibility modifications, job placement assistance, attendant care referral, assistance with transportation, independent living training, and preventive services. There are now five centers for independent living in Minnesota located at Rochester, Marshall, St. Cloud, Hibbing, and the Metro area.

People are better off in community programs—they are happier, receive more benefits, at less cost.... The people who make the greatest gains in the community are those with the most severe and profound handicaps (Conroy, 1986).

Impact of Developments

A number of outcomes have clearly resulted from the new approaches in the area of developmental disabilities:

- There is a wider array of residential services in Minnesota.
- Fewer people are living in regional centers, and fewer are entering them.
- More people, especially children, are able to live with families and in smaller community alternatives.

The new way of thinking is shaped increasingly by the benefits of having a real home and by the support and relationships possible in a real home. On the other hand, our way of acting seems determined more by federal funding. The State of Minnesota has taken advantage of the Home and Community Based Waiver and federal funding for Foster Care. In addition and without federal assistance, Minnesota also has funded the Family Subsidy and Semi-Independent Living Services programs. Together these programs serve 22 percent of the total number of people served, but consume 17 percent of the funds.

The nature and quality of residential services for people with developmental disabilities are shaped in major ways by the size of budget appropriations and the terms and conditions of funding. It is extremely difficult to compare the costs of various residential service options because of varying definitions, assumptions, accounting procedures and economic concepts—none of which are readily apparent in the reported funding figures. Limited, comparative cost information, however, is useful for two purposes: 1) it includes total and unit costs of particular residential services; and 2) it indicates the sources of funding which would require change in order to affect the nature of residential services provided.

Table 3 presents each level of government's expenditures for the various residential services and facilities in Minnesota. The data are accurate, but direct comparisons between services are not possible for several reasons. For example, regional centers involve 24-hour care in all domains of life, while community ICF/MR facilities provide a place to live with day programs, transportation, and other services provided separately. There also are differences in visible and invisible costs. For instance, the cost of caring for a child under the Home and Community Based Waiver or Family Subsidy is far greater than the public expenditures for these programs. They are paid out of family income or provided "in kind" by parents, guardians, relatives and friends.

Total Federal, State and County Expenditures for Publicly Subsidized Living Arrangements for Minnesotans with Developmental Disabilities: FY 1986

Table 4

Regional Centers	$ 51,175,470	$ 40,554,360	$ 4,827,900	$ 96,557,730	2,124
Community ICF/MR Facilities	56,885,960	45,079,440	5,366,600	107,332, 000	5,840
Nursing Homes	11,677,028	9,253,495	1,101,607	22,032,130	1,339
Home and Community Care Waiver	2,725,260	2,159,640	257,100	5,142,000	570
Family Subsidy	0	705,000	0	705,000	280
Semi-Independent Living Services (SILS)	0	2,662,730	1,141,170	3,803,900	910
Adult Foster Care (not covered by waiver)	1,295,616	865,286	152,698	2,313,600	482
Child Foster Care (not covered by waiver)[b]	1,102,275	649,528	1,299,054	3,050,857	769

Sources and Formulas for Table 3

Regional Centers, ICF MR and Waiver Cost Data: FY 86.

Nursing Homes:

Family Subsidy:

SILS:

Adult Foster Care:

Child Foster Care:

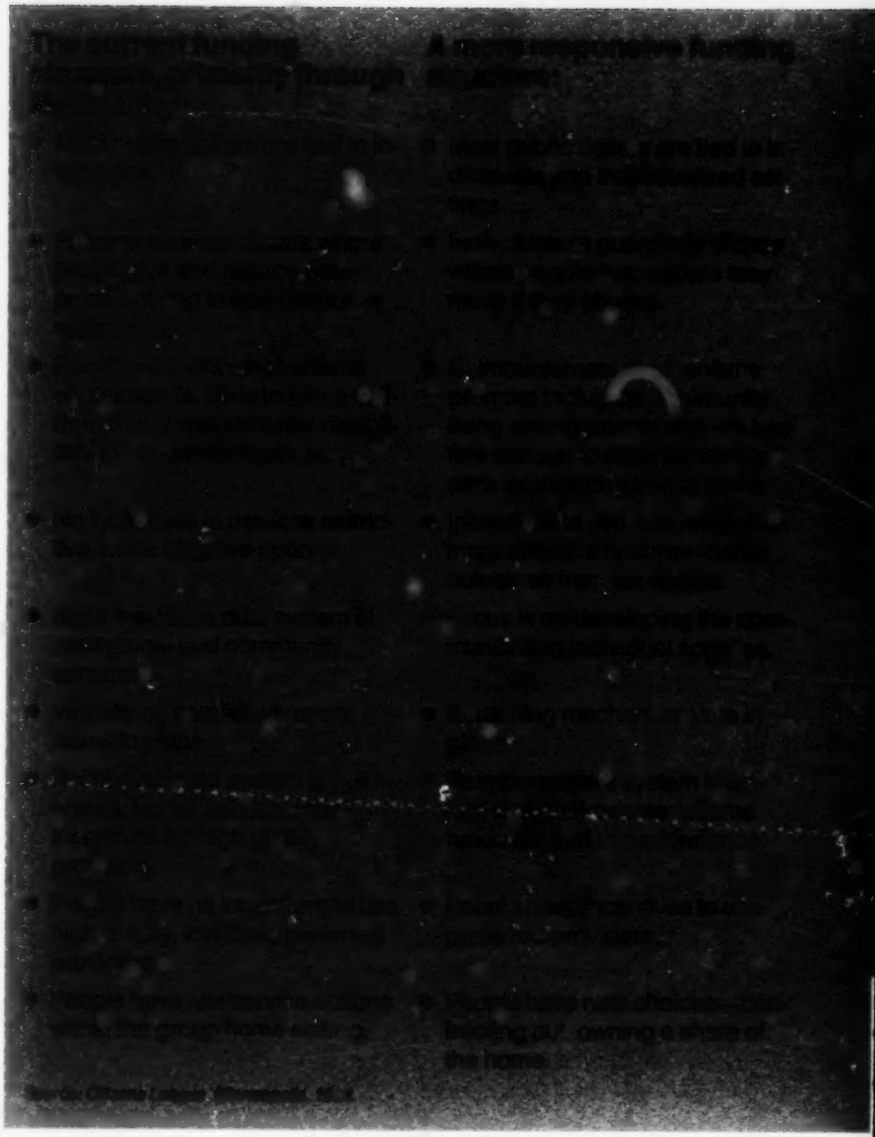
The Need for Funding Reform

The patterns in funding sources and service directions are clear:

- The Family Subsidy Programs, SILS, and Foster Care are largely state and county initiatives which prevent institutionalization, promote deinstitutionalization and support individual living arrangements. The Medicaid waiver reinforces these state and local initiatives to provide individualized support and community integration.
- Medicaid funds are the largest source of support for residential facilities such as regional centers, community ICF/MR facilities, and nursing homes. Medicaid regulations reinforce the focus on programming and congregate care.

In this context, the critical policy issue becomes one of redirecting and expanding individualized options to better meet the needs of people with developmental disabilities to live in real homes. The character of the current system clearly is shaped by Medicaid funding—about 94 percent of the $241 million spent on residential services for people with developmental disabilities is regulated by Medicaid.

Funding very definitely is determining services. Changes in policy to support individuals will require changes in funding structures. In 1984 the Citizens League studied five groups of people (elderly, juveniles, mentally ill, chemically dependent, and developmentally disabled) who live in out-of-home placements. The Citizens League identified characteristics of Medicaid funding and the corresponding reforms necessary to make funding more responsive to individual needs.



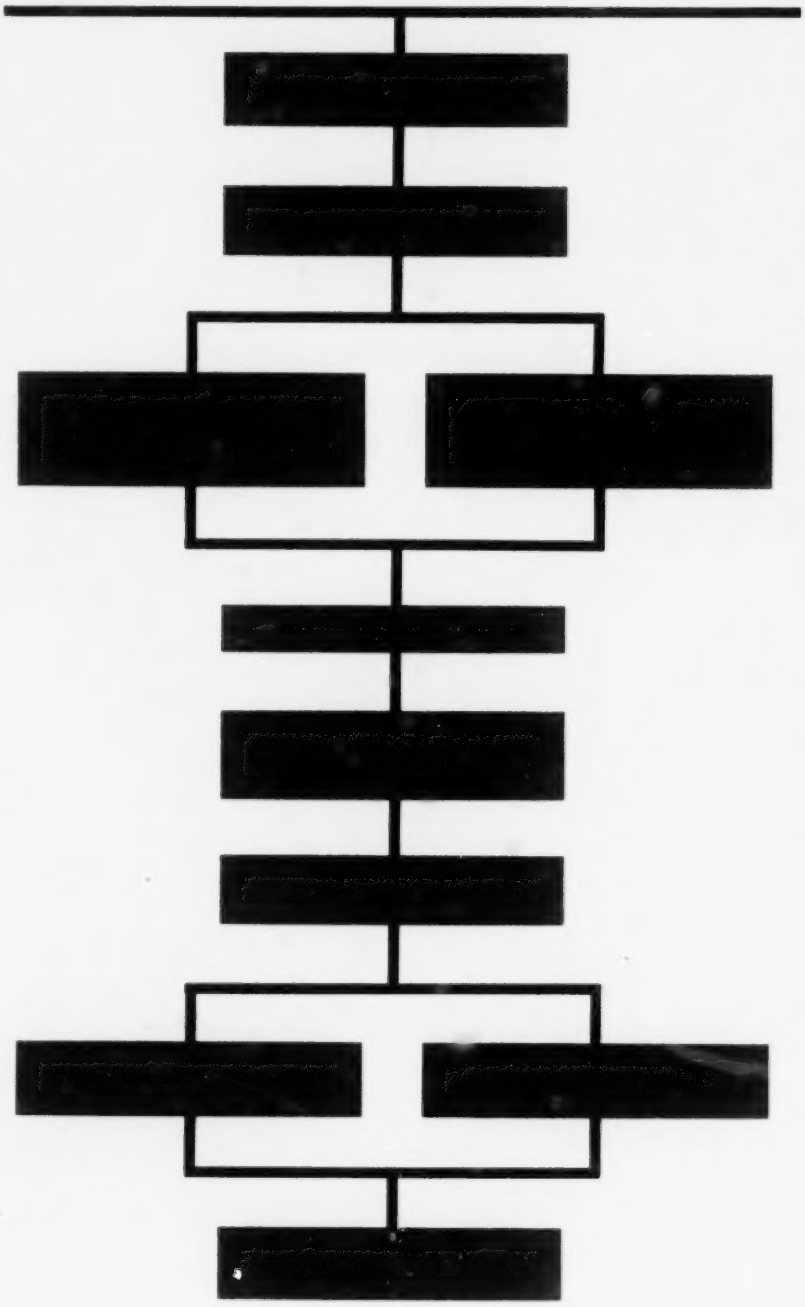
A NEW WAY OF *Working*

We have changed our way of thinking about how people with developmental disabilities can become productive citizens and make contributions to their communities. We used to spend years preparing people with disabilities for eventual work or providing them with sheltered places in which to work. In Minnesota and many other communities, we have learned that by focusing on preparing people for work, we have often created circumstances that result in people never actually getting jobs. Today we have learned that if we support individuals to find jobs, we can then quite effectively teach them the skills for that job and make adaptations to the work place that increase their ability to do the job. We can support people to work while training them on the job (see Figure 2).

We have learned that if we assist people to find, obtain and retain employment, there are significant benefits for the people as well as for society. The individuals earn a wage, have the opportunity to make a contribution to the community, are more able to learn from and develop relationships with non-handicapped people, and have greater opportunities to exercise choice in their lives. The community, at the same time, derives the benefits of their work and relates with people who have disabilities as contributing citizens.

Alternative Approach to Traditional Job Placement

Figure 2



Source: Rood, 1985.

Employment is important to most citizens and citizens with developmental disabilities are no exception. The unfortunate reality is that most of these citizens are not working. Lou Harris and Associates (1986) indicated that two-thirds of all Americans with disabilities between the ages of 16 and 64 are not working. One in four works full time, and another ten percent work part-time. Two-thirds of those who are not working said they would like to have a job.

Not only are people with disabilities excluded from places of work, they are excluded from being counted in the labor force. According to Harris, 62 percent of adults (16-64 years) with disabilities are not counted in the labor force—they are either not working or not looking for work.

Several agencies, communities, states, and the federal government are redesigning the way vocational and employment services are delivered to people with developmental disabilities. This change is most evident in the number of states receiving grants from the U.S. Department of Education Office of Special Education and Rehabilitative Services (OSERS) to establish statewide systems of supported employment opportunities for people with severe disabilities. On October 1, 1985, ten states, including Minnesota were awarded grants, and on October 1, 1986 an additional seventeen states became involved. Over one-half of the states are now initiating changes from a system of sheltered employment and day activities to one based on supported employment.

Policy and Service Developments in Minnesota

The evolution of policies and services related to employment in Minnesota has moved from the institutional approach to an individualized, supported employment approach, with many stages in-between. This progression of thinking about work for people with developmental disabilities is described below.

Institutional Approach to Work

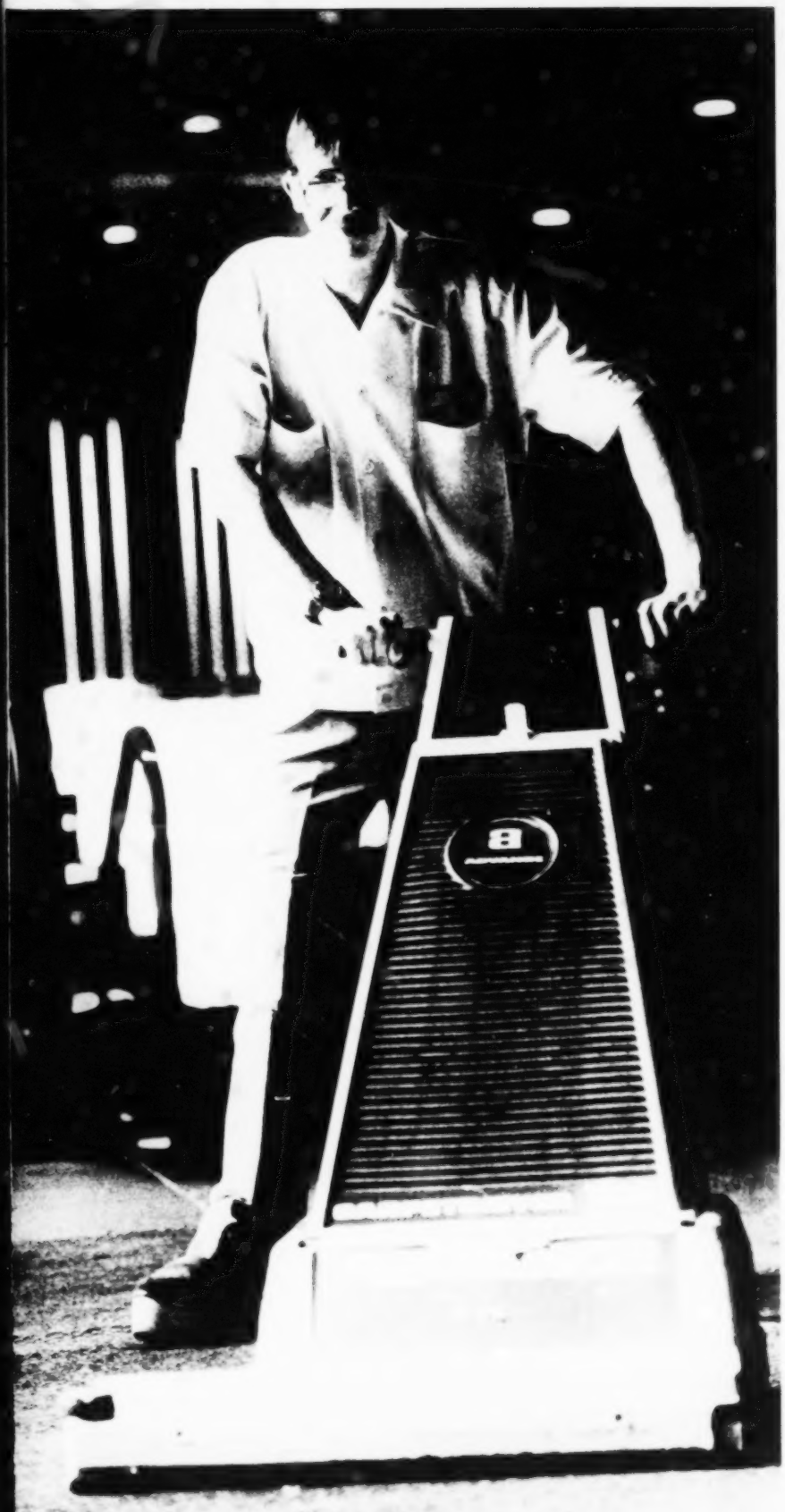
Historically, institutions employed residents in work situations within the institution, but little attention was paid to preparing them for productive work in the community. This was most evident in the involvement of residents in state hospital-operated farms. Such farms are no longer common, but there are other opportunities for work within institutional settings. During 1984, Minnesota regional centers spent $1,089,570 in pay to residents for work performed. This represented .7 percent of the total operating expenditures for the regional centers (Minnesota State Planning Agency, 1985).

Community and Individual Approaches to Employment

Over the last two decades there have been two distinct types of developments in community services related to work and employment—the early development of facilities to provide rehabilitation and sheltered employment services; and the more recent development of supported employment programs. Changes in the federal Rehabilitation Act and other legislation have reflected historical developments in each of these areas.

The Rehabilitation Act of 1973 (P.L. 93-112) authorized and supported a range of services, including:

- Vocational rehabilitation services (including medical, psychiatric, psychological, social and vocational services).
- Testing, fitting or training in the use of prosthetic and orthotic devices.
- Prevocational conditioning or recreation therapy.
- Physical and occupational therapy.
- Speech and hearing therapy.
- Evaluation of rehabilitation potential.
- Personal and work adjustment.
- Vocational training aimed at career advancement.
- Evaluation or control of specific disabilities.
- Orientation or mobility services to people who are blind.
- Extended employment (for those who cannot compete in the labor market).



This legislation led to the development of a network of facility-based rehabilitation and sheltered employment services. The 1986 amendments to the Rehabilitation Act acknowledge the new way of working. These amendments include the following important elements:

- Supported employment is recognized as an acceptable outcome for employability. Supported employment is defined as employment in an integrated setting for individuals with severe disabilities for whom such employment has not traditionally occurred.
- Severe disability is defined in terms of functioning level and extent of services required rather than a diagnostic label.
- Rehabilitation engineering is recognized as a component of vocational rehabilitation. This means the systematic application of technology to help individuals with disabilities overcome barriers in education, rehabilitation, employment and independent living.
- Individualized written rehabilitation plans are to include specific provisions for individuals with severe disabilities including a statement as to how services during employment will be provided.

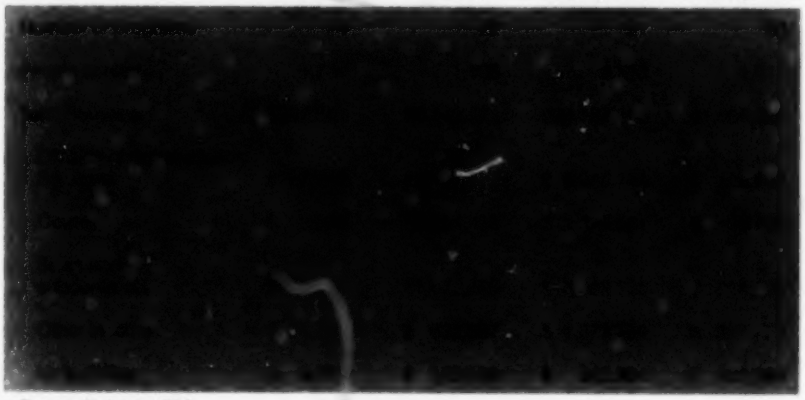
Rehabilitation Services

In 1985, there were 36 rehabilitation facilities certified, accredited and funded by the Minnesota Department of Jobs and Training, Division of Rehabilitation Services. Under the auspices of these facilities, it is possible to provide sheltered work or employment-related services including vocational evaluation, work adjustment training, work component, work activity centers, and/or long-term sheltered employment. Table 4 summarizes the number of programs in Minnesota, the number of people served, and the revenue by major source for 1985.

Numbers of Programs, People with Disabilities Served, Average Annual Wage and Revenue by Source for Extended Employment Services in Minnesota Rehabilitation Facilities During 1985

Table 4

Characteristics	Rehabilitation Extended Employment Programs			
	Work Component	Work Activity	Long Term Sheltered Employment	Community Based Employment



Source: Andrews, 1986.

Generally, people with developmental disabilities are placed in programs on the basis of assessments of their productivity level. Traditionally, individuals with the most severe disabilities are placed in work component programs; those considered more capable are placed in work activity programs; and those viewed as the most capable are placed in long-term sheltered employment. The employment services funded under the Division of Rehabilitation Services are described below.

- **Vocational Evaluation** services are intended to determine a person's job potential. In 1985, such services were provided for 1,466 clients of the Division of Rehabilitation Services. The Division allocated $625,235 in revenues from state and federal appropriations for this service.
- **Work Adjustment Training** is an extended training service designed to help people with disabilities learn specific work habits, attitudes and skills. During 1985, 1,401 individuals received this service. The Division of Rehabilitation Services allocated $1,536,662 to this service from federal and state revenues.
- **Work Component** services are provided in developmental achievement centers through cooperative agreements with long-term sheltered employment workshops which are directly affected by their production outcome. The service operates under the workshops' subminimum wage certificates. In 1985, 1,734 people were involved in work component services provided through fourteen of the long-term sheltered employment workshops. The average annual wage was $89. Total revenues supporting these services was $397,351 with 72 percent coming from the Division of Rehabilitation Services grants.

- **Work Activity Centers** provide activity for which wages are paid. The expected level of productivity is less than required for sheltered employment. Wages paid for work performed are generally 25 percent of the legal minimum wage. In 1973, the sheltered workshop law was amended to provide for such centers. By 1985, 22 of the 36 rehabilitation facilities operated work activity centers and served 1,408 participants. The average annual wage was $531 and participants worked an average of 3.4 hours a day. The total revenue available for all work activity centers during 1985 was $6,442,521. Table 4 indicates that the largest portion of this revenue came from counties and the Division of Rehabilitation Services—$4,362,010 or 68 percent. The remaining 32 percent was covered by sales, subcontracts and other income.
- **Long-term Sheltered Employment** is defined as the provision of paid employment for an indefinite period of time for people with severe disabilities who are unable to meet production standards required in competitive employment. Wages paid must be at least 25 percent of the minimum wage. In 1965, Minnesota was one of the first states to formally establish and fund sheltered employment (M.S. 129A and 8 MCAR 54.0080). By 1985, 27 of the 36 rehabilitation facilities provided long-term sheltered employment, involving 3,353 participants who worked an average of 5.5 hours per day. The average annual wage was $2,020 for participants. The total revenue in 1985 for the operation of all sites was $24,127,103. The largest source of revenue (see Table 4) was sales and subcontracts—$15,483,750 or 64 percent. The remainder came from counties, the Division of Rehabilitation Services ($6,626,585 or 28 percent) and other income ($2,016,768 or 8 percent).

Developmental Achievement Centers (DACs)

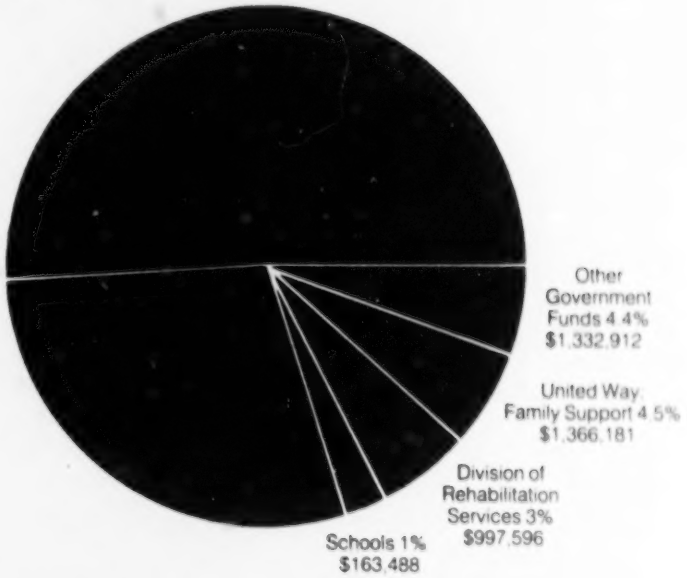
DACs are facilities which provide training, supervision, habilitation, rehabilitation and/or developmental guidance to people with developmental disabilities on a regular basis for periods of less than 24 hours a day in a place other than the person's own home. DACs were first established in Minnesota during 1961 as pilot projects. They became permanent services in 1963 (M.S. 252.21). In 1985, 105 DACs were operated by public agencies and private non-profit corporations.

A total of 6,389 people participated in DACs during 1985. More than two-thirds (4,458 or 70 percent) participated in employment/work programs. Of these, 3,340 (75 percent) were involved in projects operated within the centers, and 1,118 (25 percent) were involved in work opportunities at sites in the community with supervision from DAC personnel. Those individuals involved in DAC-based work earned an average of $151.27 a year. The highest annual wage earned by an individual involved in DAC-based activity was $3,618. On the other hand, those involved in community work earned an average of $274.04 per year, and the highest annual wage of an individual was $4,030 during 1985.

In 1985, a total of $30,098,309 was allocated for all adult DAC programs and services. The portion of this allocation used for employment programs is not known. Funding for DACs comes from federal, state and county appropriations (95.5 percent) with an additional funding from grants and donations (4.5 percent) as shown in Figure 3.

Developmental Achievement Centers Total Revenue for 1985

Figure 3


Other Government Funds 4.4% $1,332,912
United Way, Family Support 4.5% $1,366,181
Division of Rehabilitation Services 3% $997,596
Schools 1% $163,488

Source: Minnesota Department of Human Services, 1985

Integrated Employment Opportunities

Both developmental achievement centers and rehabilitation facilities are providing work opportunities outside of facilities using community based employment and supported employment approaches at sites in the community.

Community Based Employment (CBE) programs provide the following services and opportunities:

- Work and service hours outside of long-term sheltered employment facilities at minimum wage or a lesser rate if paid under the subminimum wage certificate.
- Subsidy to the employer.
- Full time or 30 hours of on-the-job training.
- Frequent daily interaction with other, non-handicapped employees.
- Appropriate development of the individual's vocational potential.
- Supervision from the long-term sheltered employment staff.

In 1985, 30 rehabilitation facilities were offering these services to 1,017 individuals. It is estimated that 1,684 will participate in 1986. The average annual income in 1985 was $410. This figure appears low because individuals are dropped from the program and considered competitively employed once they have developed sufficient proficiency on the job. The primary limitation to community based employment is that training and support for each individual are only funded for two years.

Supported Employment programs provide intensive, ongoing services required by people who are unable to secure and maintain competitive employment. The intent is to provide long-term support, or support as long as it is needed. The U.S. Department of Education Office of Special Education and Rehabilitative Services (OSERS) defines supported employment as follows:

Supported employment means paid work in a variety of integrated settings, particularly regular work sites, especially designed for severely handicapped individuals, irrespective of age or vocational potential for: 1) people for whom competitive employment at or above minimum wage traditionally has not been available; and 2) people who, because of disability, need intensive ongoing post employment support to perform in the work setting.

Supported employment is further outlined in OSERS guidelines which specify the minimum criteria as:

- At least 20 hours of paid work per week;
- No more than eight persons with disabilities served at any one job site; and
- Ongoing publicly-funded support.

These guidelines show how supported employment differs from traditional services. Traditional services focus on short-term assistance and training in order to produce long-term employment. For people who have the most severe disabilities, short-term support is not sufficient for obtaining and maintaining employment. Ongoing support can mean:

- Job analysis—matching individuals wih jobs.
- Job training—teaching social and work skills required on the job.
- Ongoing follow-along on the job for as long as required.
- Transportation.
- Ongoing support to the employer.

Rosemary, a cleaning person, works in a supported employment project for the Radisson University.

The activities carried out under the McKnight Foundation's program helped to "humanize" the system (Patten, 1985).

"The key words are self-sufficiency, productivity, and integration into the community" (Dr. Jean Elder, Assistant Secretary, Human Development Services, U.S. Department of Health and Human Services).

For each individual, there may be variations in the amount of support provided over time, the degree of social and physical integration with non-disabled workers, and pay options. Other variations of these approaches are being explored and developed in Minnesota. In particular, the McKnight Foundation, the Governor's Planning Council on Developmental Disabilities, the Division of Rehabilitation Services, the federal supported employment grants and local providers have been instrumental in developing supported employment as both a program and an outcome in the state.

In 1982, the McKnight Foundation's Developmental Disabilities Grant Program targeted systems change, including change in employment services. One result of the McKnight effort was more openness to new ideas and new ways of creating work opportunities. The Governor's Planning Council on Developmental Disabilities Employment Grants helped establish more creative employment opportunities across the state. As a result over 950 persons were employed in the community. The 1986 OSERS project provided the context for a joint agency venture in Minnesota involving the Department of Human Services, the Department of Jobs and Training, the Department of Education, and the State Planning Agency. Concurrent with, and as part of these initiatives, there has been a series of conferences and consultations. These have involved state conferences with national leaders in supported employment, activities related to educational integration and vocational training, and training aimed at raising parental expectations.

Some of the effects of supported employment services identified by local providers include the following:

- As a result of the achievements made by people who have been placed, many professionals have changed their perceptions about what is possible.
- The retention rate in community job placement has been higher than expected.
- Community job placement typically has been accompanied by improvements in grooming, posture and behavior.
- Community job placement has been accompanied by movement to less restrictive places to live (Ron Kaliszewski, personal communication, 1986).

In addition to these efforts, the five-year project funded by OSERS called "The Minnesota Supported Employment Project," has identified as its purpose supporting people with the most severe disabilities and assisting them to obtain and retain employment. Six supported employment programs are now underway. The goal for the first year was for the six agencies to make a combined total of 75 placements of people with the most severe disabilities in supported employment situations.

Impact of Developments

During the last few years in Minnesota there has been an emergence of statewide and concerted efforts to secure and support employment for people with developmental disabilities. Increasingly, attention is shifting to a concern with real work for pay alongside non-disabled people. The impact of higher expectations, innovative projects, conferences and consultations is being felt. The system is progressing, but it has far to go in addressing the underemployment, inappropriate employment or complete unemployment of individuals with disabilities.

Certainly the application of the supported employment approach is consistent with the new way of thinking about people with developmental disabilities. The momentum is building and as we gain experience with this new way of creating opportunities, many issues are becoming clearer:

- Once again, funding regulations are often inconsistent with the more individualized approach. For instance, developmental achievement centers are natural providers of supported employment programs, yet with Medicaid as the primary source of revenue for DACs, funding restrictions in the area of employment make leadership by DACs difficult.
- To make supported employment a permanent and integrated part of policy and practice, it should be included in state statute and funds should be allocated. To date, operational guidelines for supported employment have been determined by the terms and conditions of the federal OSERS grant and by recommendations in the professional literature.
- The change in both policy and practice from segregated work sites to more dispersed employment in integrated settings requires skills and values training for service organizations and staff, a different approach to monitoring, and support to the parents and guardians of people with developmental disabilities.

Another viewpoint is outlined in the following passage coauthored by Dr. Jean Elder, Assistant Secretary, U.S. Office of Human Development Services:

One of the most pervasive problems with today's public programs is the major work disincentives that they create, particularly by the income support and health care programs. These programs create work disincentives in at least three different ways: (1) by reducing the net gain from work, (2) by fostering dependency and negative attitudes toward work, and (3) by offering greater income security to persons who continue as beneficiaries of these programs than could be obtained in regular employment (Conley, Noble and Elder, 1986, p. 65).

Recent Congressional action addressed fiscal disincentives for workers and is helping to build momentum for individualized employment support. Section 1619 of the Social Security Act was enacted as a 3-year demonstration project effective January 1, 1981 (made permanent in 1986) to remove work disincentives for recipients of Supplemental Security Income (SSI) disability benefits who work despite continuing disabilities. Prior to enactment of Section 1619, recipients could lose eligibility for cash benefits and Medicaid coverage if they engaged in substantial gainful activity. Section 1619 contains two basic provisions:

- Section (a): Extension of cash and Medicaid benefits to individuals whose earnings prevent eligibility for regular SSI cash benefits (as income increases, cash benefits are reduced);
- Section (b): Extension of Medicaid coverage to individuals whose earnings, although high enough to prevent eligibility for SSI, are not high enough to cover medical care.

SUPPORTING A NEW *Vision*

There are three major messages in this report. First, there is a **new way of thinking** about how, where and with whom people with developmental disabilities can live, learn and work. This new way of thinking has involved a shift from a preoccupation with preparation, care and treatment to a concentration on supporting participation, building on capabilities, adapting environments and building relationships. The old way of thinking meant offering individuals and families a limited number of options. The new way of thinking means assisting individuals and families in identifying what is important to them, and empowering them with decisionmaking and spending authority to act upon those choices.

Second, the policies, funding mechanisms and services developed in Minnesota represent our best efforts in light of what we have known. Recently, though, policies and innovations in funding have encouraged us to **explore new service strategies** and develop experience with new ways of thinking and acting.

Third, the impact of these developments in new policies and services has **not yet tipped the balance** in the life experiences of people with developmental disabilities. Madeleine Will, Assistant Secretary of the Office of Special Education and Rehabilitative Services, summarized the new vision when she stated:

Citizens with developmental disabilities want the same opportunities and ought to have the same opportunities as other members of the community—not because it is cost effective, even though it is, and not because it is prudent, even though it is. They should have the same opportunities because they deserve it (Will, 1984).

There are many national, state and local initiatives which support and build on changes in the field of developmental disabilities. In the future, we will look back on these initiatives as milestones. Today they serve to illuminate the reforms which are underway in the current system.

Federal Funding Reforms

During 1986 there were numerous presentations to Congress and government agencies concerning the constraints of Medicaid funding on the abilities of states and communities to implement the new way of thinking in a systematic and reliable way. Medicaid funding consistently supports institutional approaches and, according to Senator Lowell Weicker, "... results in the isolation, segregation, and dependency of individuals" (Weicker, 1986). The Home and Community Based Waiver is a beginning step in altering this situation. The waiver program has enabled many states to offer some support services to families. There is potential for the waiver to provide the flexibility needed to develop services and supports which will enable people to live in real homes and work in real jobs. If the potential of the waiver is to be realized, however, it will be necessary to reduce restrictions, expand the number of people who can be served, and make the waiver permanent.

It's a familiar story, replayed thousands of times daily across the nation. A lack of openings in existing day programs and residential services leading to seemingly endless waiting lists. It's a crisis that's getting bigger every day as the deinstitutionalization movement grows, and as more people with mental retardation graduate from schools, ready to enter the community (Association for Retarded Citizens-United States, 1986).

Recent amendments to the Medicaid waiver (P.L. 99-272) are in line with these needed reforms. The amendments explicitly authorize Medicaid funding for supported employment services for individuals who are leaving ICF-MR facilities. The amendments permit states to request a five-year, rather than a three-year, renewal of existing waiver programs and the amendments authorize coverage of case management services.

The waiver is one step in the right direction. There is a clear need for purposeful restructuring of Medicaid funding. One of the key elements of funding reform must be the need for funds to meet the unique needs of individuals, in contrast to the current system of funding programs. The spirit of funding should reflect that of the Education for All Handicapped Children Act (P.L. 94-142). Much can be learned from P.L. 94-142 and its focus on integration and individualization. The reallocation of Medicaid funds to support the development of individual and community services is required to serve and respond to the needs of three groups of people with developmental disabilities:

- Those currently living in institutions, all of whom would benefit from life in the community,
- Those currently being served by community programs which are seeking to redesign their services to conform to the new way of thinking, and
- The large numbers of people who are receiving no services.

The needs of individuals in institutions and of those currently receiving inappropriate services in the community have been a decided source of pressure for change. An even greater potential source for change lies in the unmet needs of individuals who are waiting for services.

Developing Alternatives to Institutional Care

A prevailing theme in the new way of thinking emphasizes the increasingly shared belief that people with developmental disabilities should live in the community. There is growing support across Minnesota and across the country to phase out institutions and develop community alternatives.

Rhode Island Eliminates Institutional Care

On July 30, 1986, Rhode Island Governor Edward DiPrete announced that the Ladd Center would be closed within five years. This will mean that Rhode Island will be the first state in the country to eliminate institutional care for its citizens with developmental disabilities.

Mission of Connecticut Department of Mental Retardation

On February 13, 1986, the Department of Mental Retardation in Connecticut approved a new mission statement indicating that it will join with others to create the conditions under which all people with developmental disabilities experience:

- **Presence** and **participation** in Connecticut town life;
- Opportunities to develop and exercise **competence**;
- Opportunities to make **choices** in pursuit of a personal future;
- Good **relationships** with family members and friends; and
- **Respect** and **dignity**.

Minnesota Counties Set Goal to Return All Residents in Institutions to Their Communities

Dakota, Ramsey and Wadena Counties in Minnesota have each declared that they will return all people in regional centers to community placements in their county of residence. This means that these counties will actively develop or stimulate the development of appropriate community arrangements for the institutionalized individuals under their jurisdictions. There were 66 counties in Minnesota, as of November, 1986, with no children in regional centers.

County Initiative to Diversify Services

Wadena County has allocated county resources for a contract with a local ICF/MR facility to develop a SILS program and other diversified services. This would permit residents of the ICF/MR facility to move to community living arrangements and, in turn, for county residents currently residing in the regional center at Brainerd to move to the ICF/MR. State policy should support local efforts to provide services in the community by allowing resources to follow the person to the most appropriate residential arrangement. Incentives should also be provided to ICF/MR providers to diversify their services to meet the needs of their residents, rather than requiring residents to fit into the programs of the facilities.

Promoting Individualized Options

Across the country and state, there are a number of initiatives which seek to support people with developmental disabilities as individuals and as members of the community. Some examples of local initiatives follow.

Partnership for Quality Services

This demonstration project is designed to maximize the skills of parents and promote cooperation among parents, professionals, service-providers and community members to establish mechanisms for monitoring programs and ensuring quality standards. The project is funded by the Governor's Planning Council on Developmental Disabilities, and is conducted by the Association for Retarded Citizens-Minnesota.

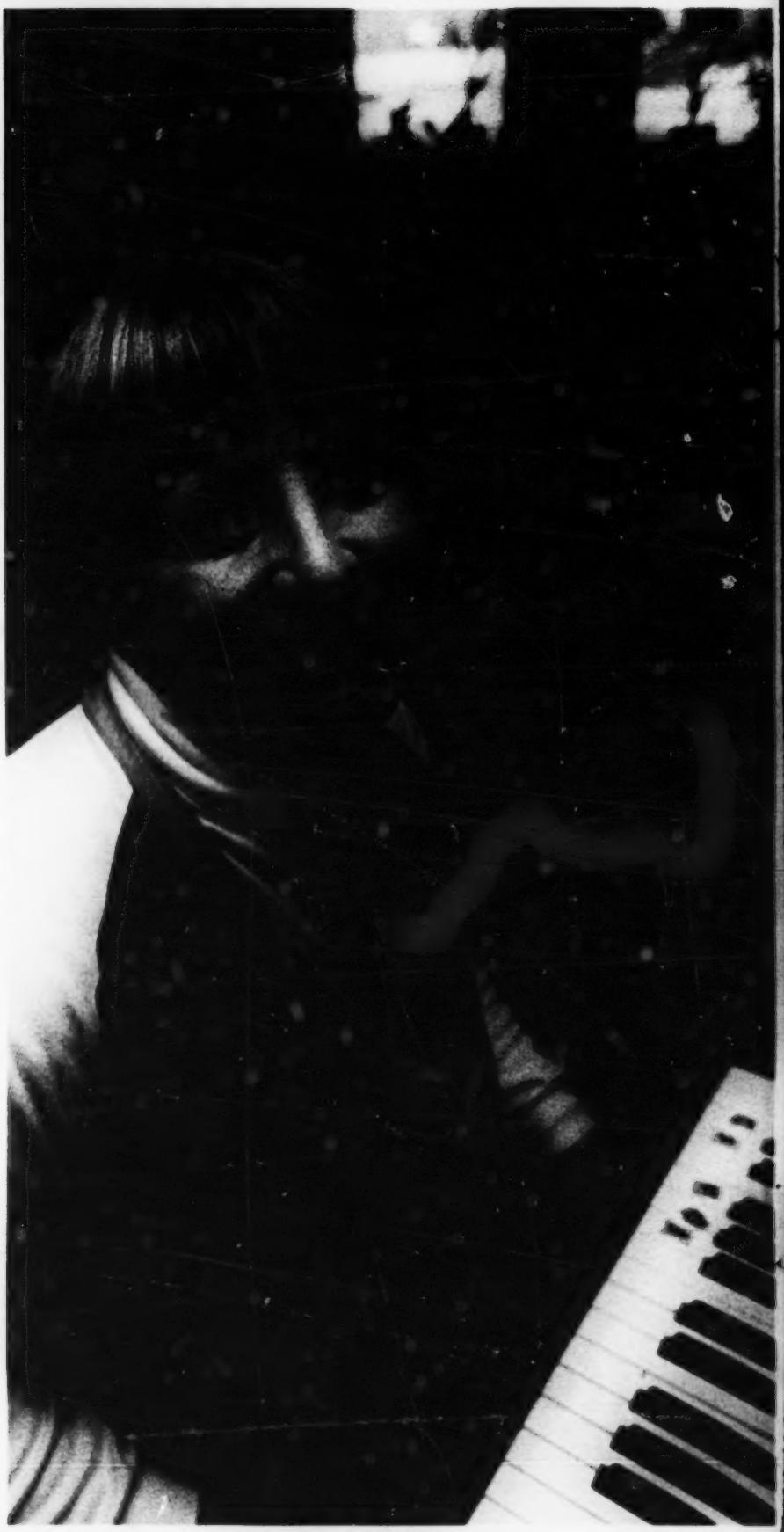
The new way of thinking requires a different orientation to quality assurance and evaluation. This project addresses this issue. The focus on real outcomes and a concentration on the strengths and needs of the individual mean that inspections, licensure and traditional evaluation approaches are not appropriate.

Through this project we light the way toward a future in which care for retarded citizens in this nation no longer need include large, impersonal institutions. This commitment to dignity, quality and compassion is in the finest traditions of our state (DiPrete, 1986).

It's the beginning of the end of institutional care.... Institutions are not appropriate places for people to live (Robert Carl, Director, Rhode Island Mental Retardation Division).

"The real issue is quality of life, not quality of care" (Jerry Provencal, Superintendent of Macomb-Oakland Mt. Clemens, Michigan).

No matter how much money is spent and how well-intentioned supports and services are, the lives of people may not be significantly altered unless there is a way of assuring the quality of those supports (Bruce Kappel, G. Allan Roeher Institute, Toronto, Canada).



Alternative Case Management Delivery

In Dakota and Washington Counties, a project is underway to explore the feasibility and value of having parents serve as case managers for their children with developmental disabilities. By building on the interests and talents of parents, the project hopes to encourage parent leadership resulting in better and more cost-effective services. The project is funded by the Governor's Planning Council on Developmental Disabilities and directed by the Association for Retarded Citizens-Suburban. It provides training and support to parents who are interested in managing their children's services and plans. Parents will receive training and a minimal monthly stipend to coordinate activities and services for their children with the county case manager serving as a facilitator. A modified voucher system based on a range of needed services will be used by the county to disburse funds according to the parent-set plans.

Cooperative Consumer Owned Housing

Several Minnesota families are embarking on cooperative ventures to purchase or lease a house or apartment for their children with developmental disabilities. Families contract directly for support services, and own and manage the housing. This enables their sons and daughters to live in the community in a home of their own with control over the amount and kind of services or supports necessary.

Regional Cooperation to Make Waivers Available Where They are Needed

Eight Minnesota counties (Beltrami, Cass, Clearwater, Crow Wing, Hubbard, Morrison, Todd and Wadena) have entered into a regional cooperative arrangement for using waivered services. The arrangement is coordinated by the Regional Services Specialist, an employee of the Department of Human Services. This cooperative allows the counties not making use of their allocated waiver positions to make them available to the counties needing them.

The initiatives outlined above are helping to create a new vision in Minnesota. The translation of that vision into reality statewide will depend on two changes:

1) Major reforms in federal funding to encourage the routine and systematic development of services and supports to individuals as participating and contributing members of their communities.

2) Systematic attention at the state, local, family and individual levels to ensuring that the vision is achieved.

Professionals need a sense of urgency in getting people with developmental disabilities out of institutions. We in America have no patience for waiting so why do we expect people with disabilities to wait while we plan their lives (Jerry Provencal, Superintendent of Macomb-Oakland, Mt. Clemens, Michigan).

Supporting a New Vision—What Can Minnesotans Do?

Consumers and Parents

- Participate in team meetings and individual planning sessions and ask questions linked to important aspects of your life:
  - How will this plan or series of activities assist the individual with a disability to live and participate in the community?
  - Would this objective or activity be appropriate for a person of the same age who is not disabled?
  - Is this objective or activity geared to the future and where the person will be living and working?
  - Is the development and support of friendships for the person with disabilities a part of the plan of action?
- Visit other programs, find out what they are doing that is useful, and ask questions of other parents and consumers about what they find helpful.
- Join other individuals and organizations such as the Association for Retarded Citizens, the Association for Persons with Severe Handicaps, and the United Cerebral Palsy Association and other groups to help make reforms in the system.
- Find out what is possible and request that service providers also know the state of the art.

As Policymakers

- Ensure that funding is linked to the achievement of valued outcomes. Welcome and be prepared to answer questions about why a service is being funded and whether or not it leads to independence, productivity, and integration.
- Make it a point to visit services and programs regularly, and talk with the people whose lives are affected by them.
- Increase the incentives and recognition for providing quality services.

As Professionals and Board Members

- Be aware of state of the art programs.
- Review your practices to ensure that individuals are treated with respect and dignity.
- Revise your program goals and objectives to ensure that activities are age appropriate, functional and community referenced.
- Respond to the needs of people as individuals and ensure that they are involved in decision-making.
- Continually ask—are we doing the right thing? Request regular and frequent feedback from consumers and families.

As a Citizen, Friend, or Neighbor

- Use your relationships in the community to help people with developmental disabilities become part of the community.
- Welcome individuals with disabilities into your neighborhood, school, business, church—be a friend.
- Visit the services offered by your community. Question whether the services support and include individuals with developmental disabilities.
- Think about how many friends you have who are not paid to talk to you, and compare that to the number of friends in the lives of people with disabilities.

As a Community

- Think about ways to ensure that people with developmental disabilities have the opportunity to live in homes of their own rather than service settings and to be real neighbors.
- Look around your community and discover who is missing or has had to leave your community because services and supports were not available. Consider what you can do to help them return home.
- Set an agenda for creating a community that welcomes, includes and supports people with developmental disabilities.

"All communities depend on the capacity of people—on their fullness, on their possibility—the heart of community is 'capacity.' If we want to create community we build on capacity of the individuals we serve and not on needs."

(John McKnight, Associate Director, Center for Urban Affairs and Policy Research, Northwestern University)

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